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Parent of 13 year old daughter with Autism

While I am a parent of a child with autism, I am speaking to you first as the Chief Financial Officer (CFO) of one of Michigan's largest companies employing almost 10,000 people directly and indirectly employing many more.

I would like to talk to you about the economics or finances related to the matter at hand and give you my perspective as a CFO and Business Leader in Michigan.

When I approached this issue of autism insurance reform, I went about my research as I would do any other business proposal. Every day I am asked to look at complex financial proposals to make capital investments within our multi billion budget. These are complex financial proposals with multiple drivers and timing issues. These proposals often involve spending money up front to save substantially more money over time, or one group within the organization making an investment, but the benefit shows up in another department. Autism insurance reform is no different from a Business and State of Michigan perspective. The economics of this proposal are sound and the payback is significant.

To learn more about this, I have studied every available analysis on this matter. For example, in Pennsylvania there was an independent study done resulting in a 55 page report. This was performed by independent PhD's in health research, biostatistics, economic research and insurance/actuarial research. Similar independent studies have been done by Mercer Consulting, Oliver Wyman and the Texas Council on Autism. All studies on autism insurance reform reach very similar conclusions. As with any business proposal that I review and approve, I have spent a significant amount of time with the numbers and I am convinced this insurance reform proposal is unique and compelling in the conclusions.

I have also spent time with James Boudier's Benefit and Cost Analysis of Michigan Autism Insurance Coverage. I agree with the analysis and conclusions and offer my full endorsement.

- Over the lifespan of a person with autism the average cost of caring for that person is about \$3.7 million. Most of the costs are incurred in adulthood and are, in part a direct result of not receiving services as a child.
- Nationally the cost is over \$90 billion annually and growing.

- The costs of autism are here today. This is the base cost case that will be reduced with this reform. For the approximately 14,000 children in Michigan with autism – this represents a cost of \$45 billion over their lifetime. These costs are embedded costs and are currently paid for by the State of Michigan, its businesses and its citizens.
- Research has shown that the earlier the treatments, the greater the positive impact on the child. If not treated, in many cases the child will likely require full time care for the rest of their life.
- Early assessment is critical. Some states are promoting assessments as early as age two. Today the average assessment and determination is at age 6, long beyond the formative years of the brain.
- Early assessment will drive demand for services, but without insurance coverage there is little hope of the children receiving the much needed therapies.
- The cost for non treatment is incurred by Michigan's Businesses, the State of Michigan and families – if they can afford it. Many families of children with autism incur financial distress including bankruptcy.
- Because of the exclusions included in insurance policies it is estimated that 2/3rds of children with autism do not receive the much needed therapies that can be a gift of life and independence for them and their families
- Some States provide oversight for autism. For example The Texas Council on Autism and Pervasive Developmental Disorders was established by legislation in 1987. The Texas Department of Aging and Disability Services provide administrative support for the Council. The Council's mission is to advise and make recommendations to state agencies and the state legislature to ensure that the needs of persons of all ages with autism and other pervasive developmental disorders and their families are addressed and that all available resources are coordinated to meet those needs. The council is composed of seven public members, the majority of whom are family members of a person with autism or a pervasive developmental disorder, appointed by the governor with the advice and consent of the Senate. Florida has similar oversight.

A study published by the American Academy of Pediatrics in 2008 looked at families of children with autism and compared them to families of children with other special health needs and found that:

- Families of children with autism incurred large out of pocket expenditures, experienced severe financial problems, had lower physical and mental well being and had to stop or reduce work to care for their child.
- The children had less access to important healthcare, reported problems with referrals, coordinating care and obtaining family support services.
- 90% of children with autism have multiple concurrent disorders including epilepsy, gastro-intestinal problems, anxiety, depression and allergies.

This results in additional financial burdens, increased stress, strain and mental health issues for families. In fact the stress is so high, research shows parents of children with autism have higher medical bills brought on stress. Worst yet – it is estimated that 90% of

parents of children with autism are divorced. Many of these divorces are a direct consequence of the stress of raising a child with autism. Proper and timely treatment will significantly reduce the pressure on vulnerable families. These divorces compound the issue of child care for the child with autism.

Research done by the Interactive Autism Network in April of 2009 shows:

- The majority of families report significant stress driven by behavior issues, the required hyper vigilance and social isolation
- 48% report exhaustion and sleep deprivation
- 70% report moderate or a great deal of stress impact caused by difficulty in getting services. “I am so tired of fighting”, one discouraged parent says in the report. Another says, “We are told early intervention is vitally important, but we have no support in getting or paying for the services. We are completely on our own to help our child”.
- Almost all parents of children with autism report moderate or a great deal of stress due to worry over their child’s future. As one parent reports, “I have to put this out of my mind every day because it can put me into depression ... but it really breaks my heart every moment of my life”.

As a Michigan employer, if I have an employee who has a child with autism – chances are that they or their spouse will have reduced work hours or have to give up their job. If they are working – they cannot be fully productive – chances are they are divorced, interfacing with multiple therapists, experiencing extreme financial difficulty and themselves experiencing stress related medical conditions.

Also as an employer – employees’ children are covered on DTE’s medical insurance policy through college until age 25. This is common. If a child is not independent, they are covered for life on our medical policy. This is also very common. Since there are therapies that have a high probability of providing independence and moving children with autism off our insurance by age 25 – we have a vested interest in providing insurance coverage for autism. DTE believes the math is so compelling that we are currently considering self adopting coverage for therapies for children with autism. DTE would join companies like Eli Lilly and Microsoft in doing this as well as the Department of Defense.

For those that think we are currently saving money as businesses and society by taking no action – they wouldn’t get many investment proposals by me. The cost of not acting on this reform proposal is the high cost option.

Autism is fastest growing developmental disability in the world today. It is an epidemic. While 1 in 150 children have some form of autism, it is increasing at an alarming rate. In New Jersey it is 1 in 80, in England 1 in 60. While researchers, including Michigan-based researchers at The University of Michigan, Wayne State University and Children's Hospital of Michigan are looking for answers, – we as leaders in the State of Michigan have to deal with the reality we have today.

Research now shows that early diagnosis and mainstream therapies such as behavior therapy, speech therapy and occupational therapy can make a significant difference so the symptoms are not disabling – allowing a majority of these children to learn and shift from becoming lifelong dependents on the State of Michigan to becoming independent members of society and in many cases going on beyond high school to live independent lives and being a taxpayer, not a tax consumer.

So the costs are here today - \$45 billion for the current population of children with autism and this doesn't include the current adult population or the 800 children born each year with autism in Michigan.

The premium increase to cover these medically proven, evidenced based therapies is modest. In the States that have implemented this reform it is significantly less than one percent increase.

As I discuss this reform proposal with Business Leaders and State Legislators there are legitimate concerns and issues that have come up. These concerns are similar to the ones that surfaced in the 13 States that have passed this legislation. Here are some of the concerns I hear from Michigan Leaders:

How can we consider this given what is going on with the Auto Companies and the State's Economy and Budget?

Having worked for Chrysler for 14 years and seeing the direct impact on the State, DTE Energy and others, I am well aware of the economic environment we are in today. My heart goes out to the families impacted by the high unemployment caused by this financial crisis.

The reality is the costs of autism are here today. The costs of autism are inflating at 14% per year making it the fastest rising cost in healthcare. This legislation is a cost savings move. The cost of doing nothing is that these expenses stay embedded in the cost of doing business in Michigan and that 2/3rd of the children with autism don't receive the services they need.

But won't this add more costs at a time of economic duress in Michigan?

The cost increase is small and it is expected that it would take a minimum of several years after legislation for the supply of providers to increase and for parents to more aggressively seek services for children with autism. Research in Texas shows that after their legislation near term costs were significantly less than modeled when the insurance was proposed. Aetna's experience in Texas was 1/10th of one percent post insurance reform.

Many of the therapists who could treat children with autism that graduate from Michigan colleges currently leave the State for jobs in other parts of the country. This reform translates into job opportunities for our Michigan college graduates.

How much can this Insurance Reform provide in Savings?

For the current population of children the estimated savings is over \$14 billion. I believe this is a conservative estimate. This reflects the savings for the current population of children with autism and doesn't take into account the over 800 children added to the population of children with autism in Michigan every year.

What are the savings to the schools?

Research projects savings of over \$200,000 per child with autism over the ages of 3 to 18. For the Michigan population of children with autism this is \$2.8 billion in cost savings to the schools.

I don't believe in mandates and believe this will add costs as all mandates do.

As a business leader we are wrestling with healthcare every day. Our active employee healthcare cost rises every year and retiree healthcare inflation tends to be double digit. Healthcare costs challenge every business in Michigan.

I am concerned with mandates also. At the same time removing exclusions that are discriminatory, have no basis in science and cost businesses and the State of Michigan money is financially prudent. Taking no action is a mandate for higher costs.

As a Business Leader, why do you believe these medically proven therapies are excluded from insurance policies?

I can't come up with one good reason. My only thought is that at one time the medical community believed autism was not treatable.

What protections would the Business Community look for?

In talking to my counterparts in many businesses, as well as the State Chamber there are concerns about costs. I believe that all of the concerns can be addressed.

Now I would like to speak briefly as a parent. After raising three boys who are in or beyond college, this was my family's first exposure to autism, special needs and our special education system in the public schools.

Due to the lack of trained Doctors, Therapists, Teachers and other professionals, Maribel was age eleven when we first received a clear diagnosis and treatment plan. This is not uncommon. Although early intervention is critical, research shows the average assessment still happening at age 6 which is too late.

Autism takes a huge toll on everyone in the family – parents, grandparents, siblings, neighbors and friends. For years we were told – even without a diagnosis, that nothing could be done for her speech, social and behavior delays. Then for years we were told therapies could help, but we had to pay – starting with \$3,000 to get a good assessment from the University of Michigan Autism Center and speech therapy, sensory integration therapy, psychological services and behavioral therapy. We knew therapies could help and I could afford to pay for these, but finding trained therapists was near impossible. But this was easy compared to trying to find pediatricians, dentists and other healthcare professionals that have training in autism.

Our schools are not prepared for what they are faced with today. Given the increasing rates of autism, this will get worse. Lack of training, staffing and old school thinking puts many children with autism in an environment with minimal support and academic progress. While not the purpose of these hearings, Michigan's public schools compound this situation with the lack of training and resources as required by the Federal Law known as IDEA.

As a parent, this takes its toll. Maribel is higher functioning than many other children with autism. She has had access to behavior therapy, but in many cases too little and we hope that it is not too late. It is not uncommon for my daughter to have daily behavioral issues which puts my wife in particular on 24/7 duty. Also, it is not uncommon for my wife, Peggy to be at the school or on the phone dealing with a crisis – every single day. It is hard to get away even for a day.

It is exhausting, but we love our daughter and she has brought many gifts to our lives. We also believe she was brought to us for a reason and it starts here this morning, for us to advocate for an end to the pattern of discrimination, to promote autism insurance reform and then I will move on to Education Reform in the public schools. With passage of this legislation, the School Districts will have a significant financial benefit that can be redirected to the education of children with autism.

In conclusion

As a policy maker it is fair for you to ask about costs and outcomes. It is reasonable to ask, "Do these children get better and what does that entail"? With recent research showing almost half of the children recovering typical function and an additional 40% making significant improvement, these interventions drive measurable results. The net benefit to Michigan would be at least \$14 billion.

I believe the benefits of taking action today significantly outweigh the costs of doing nothing. I encourage you to swiftly move this legislation out of Committee and to the Full House, so we can continue our dialogue with the State Senate and move this reform into law.